In search of a problem

In Search of a Problem: Mapping Controversies over NHS (England) Patient Data with Digital Tools

Introduction

> It's no secret that Google has broad ambitions in healthcare. But a document obtained by New Scientist reveals that the tech giant's collaboration with the UK's National Health Service goes far beyond what has been publicly announced. The document--a data-sharing agreement between Google-owned artificial intelligence company DeepMind and the Royal Free NHS Trust--gives the clearest picture yet of what the company is doing and what sensitive data it now has access to. (Hodson 2016)

This is how *New Scientist* broke the story, in April 2016, that Google's DeepMind subsidiary had been granted access to National Health Service (NHS) patient data in England[1]. NHS England is a statutory universal healthcare system, free at the point of need and funded through general taxation. It operates a federated model and depends on a network of privately owned suppliers to manage its IT and data services, but it is a public body. As such, the ethical, legal and commercial issues raised by an Information Sharing Agreement (ISA) between the NHS and a wholly owned subsidiary of one of the world's most powerful tech companies provoked extensive coverage. The story

represents another turn in an eventful history of attempts to integrate patient data within a "digital first" paperless NHS (Department of Health 2012, 2014).

This history shows how patient data and its uses became the centre of unprecedented public attention. Science and Technology Studies (hereafter STS) scholarship has outlined how certain events develop into classic science controversies or public 'issues' that can be detected using particular tools and methodologies (Callon 1980, Marres 2005a; Barry 2012). The case of patient data sharing, although clearly controversial for some publics, has not taken the shape of a science controversy or public issue as defined within STS. This raises questions that we explore in this article about whether, and how, STS approaches can map events that are problematic, but do not conform to established definitions of issues or controversies.

One possible solution emerges from the recent revival of interest within STS in problems, (Neyland and Milyaeva 2016; Savransky 2018 forthcoming).[2] Perhaps

patient data is more of a problem than a public issue or controversy? In a pragmatist reading, problems emerge from, "indeterminate situations," which, in Dewey's (1938) sense, demand solutions but do not specify the manner of their solution. This formulation may offer a better fit for analyzing cases as ill-defined, multiple and elusive as the recent history of NHS patient data sharing initiatives. To test this, we staged an empirical experiment using a series of digital tools to locate and map the problem(s) posed by patient data.

This paper is an outcome of a Wellcome Trust funded project exploring the implications of digital technology and big data for the payment and provision of healthcare.[3] The project employed a mixed methodology including interviews, participant observation, documentary analysis and digital methods. We focus on the latter here for two reasons. First, quantitative, digital methods have a history in STS of being used to detect "problematic objects" such as controversies, issues, and matters of concern. Given that these problematic objects are highly distributed and unstable, digital methods or tools have been adopted as an aid in mapping their terrain (Venturini 2010). Second, digital

methodologies have inherited something of the standard critique levelled at quantitative methods, of lacking the capacity of qualitative methods to convey nuance and complexity. Our aim in using them in the project, and in focusing on them in this article, was in part an experiment in what off-the-peg digital tools can reveal and whether they can effectively represent indeterminacy. Experimenting with digital tools helps raise broader methodological concerns about the boundaries of study, the sorts of entities that are in scope and the sorts that get left out.

We begin by introducing the case of patient data sharing in NHS England's through two high profile cases: the Department of Health's care.data project and Google DeepMind's data sharing agreement with the Royal Free London NHS Foundation Trust. We move, in the following section, to describe how "problematic objects" of various types have been defined in STS. This paves the way for a review of how digital tools have been leveraged in the past to study such objects. Finally we report back on the results of our experiment in using

similar tools to locate the problem of patient data in a range of different settings.

Patient Data and NHS England

In a context in which growing, aging, and sicker populations are testing the capacities of healthcare systems everywhere to provide accessible, quality, affordable care, digital health tools and so called "big data" offer an alluring solution. Governments globally have responded with "connected," "precision," and "personalized" healthcare strategies with big data and digital innovation at their core. But, as demonstrated in recent cases across Europe and the US, strange things can happen when big health and biomedical data allow governments to think differently about how healthcare might be managed.[4] The catalyst for this paper was the passing of the Health and Social Care Act 2012 (HSC) by the coalition Conservative-Liberal Democrat government in the UK. The HSC, and the accompanying policy document, *The Power of Information*, outlined a strategy "to harness information and new technologies to achieve higher quality

care and improve outcomes" (Department of Health 2012: 4-6). The way information was collected and used was to be transformed to support an innovative, integrated and transparent "no decision about me, without me" culture. These principles seem unobjectionable, but the manner of their implementation was fraught from the outset. Controversy surrounded the HSC because it was interpreted, with cause, as an attempt to extend the scope of marketization and privatization within the NHS.[5] This led, more or less directly, to the two cases we describe briefly below: the care.data program, and the Royal Free NHS Foundation Trust/ Google DeepMind collaboration.

Care.data

The HSC's most notable features included the introduction of new data-based forms of accountability and the reengineering of primary care. Clinical data were to be combined with patient outcome and experience data to create the "highest quality of care" (Speed and Gabe 2013). At the same time, GPs[6] would assume an enlarged role, leading newly established Clinical Commissioning Groups (CCGs) with direct control over the provision of local healthcare. These

changes were designed to improve cost efficiency and quality, in part by strengthening the role GPs play in promoting public health to prevent the need for further primary and secondary care.

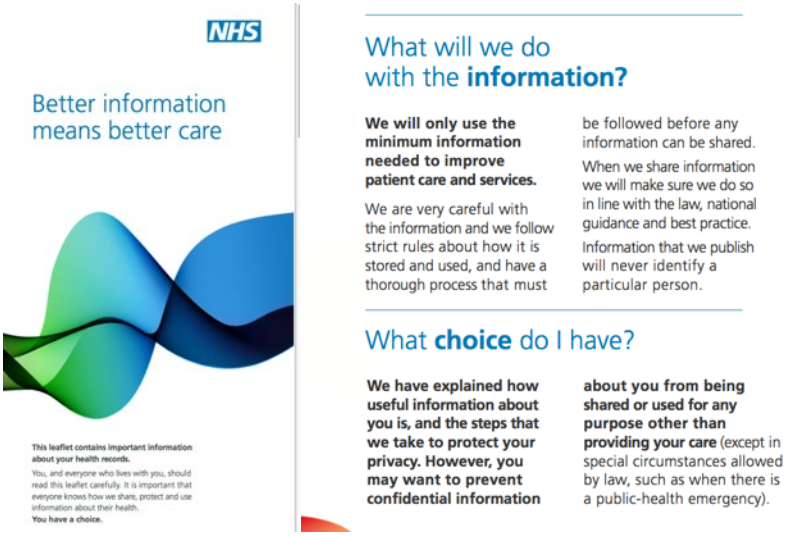
The strategy demanded new structures and processes to manage the "connected information for integrated care" that would be required. A new Health and Social Care Information Centre (HSCIC)[7] was established as the focal point for nationally collected NHS, public health, and social care data. Its objectives to make anonymized data available, accessible, and convenient, and to integrate data from different sources across primary, secondary, and social care, were prominently expressed in the Department of Health's 2012 policy document. Less prominent, the HSCIC was also charged with making its data available to third parties and "information intermediaries" to bolster the UK's position in global health industries.

> With greater access to health and care data, the UK can become a centre of excellence for health and care IT and informatics, playing a prominent part in a global industry which will deliver economic growth. [...] The ability to draw upon a wealth of linked, then anonymised, data from these invaluable services to improve health and care--when coupled with other

> resources such as the UK Biobank--will serve to reinforce this country's reputation as a global centre for health and care data and research (Department of Health 2012: 86-87).

Throughout the document, problems and their solutions were outlined in structural, plumbing-like terms. Information and data were "disjointed," duplicated, and inaccessible where they needed to flow smoothly and be shared more freely. This framing of the problem was carried into the care.data program and it likely contributed to the program's short, farcical, and well-documented history (c.f. Presser et al. 2015; Vezyridis and Timmons 2016, 2017). Care.data was meant to "securely bring together health and social care information from different healthcare settings, such as GP practices, hospitals and care homes" to be held by the HSCIC.[8] Through it, a wealth of patient-identifiable information derived from primary care, such as NHS numbers, date of birth, postcode and gender, family history, vaccinations, diagnoses, referrals, and prescriptions would be collected. In line with the objective of using the data to secure economic advantage, the program would also allow 'customers' - that is external organizations, including those from the private sector- the

opportunity to link their own data sets to pseudonymized NHS datasets (Vezyridis and Timmons 2016).


NHS

Better information means better care

This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health.

You have a choice.

What will we do with the **information?**

We will only use the minimum information needed to improve patient care and services.

We are very careful with the information and we follow strict rules about how it is stored and used, and have a thorough process that must be followed before any information can be shared.

When we share information we will make sure we do so in line with the law, national guidance and best practice.

Information that we publish will never identify a particular person.

What **choice** do I have?

We have explained how useful information about you is, and the steps that we take to protect your privacy. However, you may want to prevent confidential information about you from being shared or used for any purpose other than providing your care (except in special circumstances allowed by law, such as when there is a public-health emergency).

Figure 1. ***Better Information Means Better Care* (extract)**

In January 2014, patients were informed that the care.data program was underway by means of an NHS England leaflet, *Better Information Means Better Care*. The leaflet was produced only after pressure from GPs concerned about the way the HSC and the program approached patient data sharing. It was to be delivered to an estimated 26 million households but as an unaddressed 'flyer' that could be mistaken for junk mail it had limited impact on public awareness

(Presser et al. 2015). Care.data allowed patients to opt out of a) having their data sent to the HSCIC and b) having their data leave the HSCIC for other uses. The leaflet was meant to explain how patient information would be used and what choices patients had. Those who saw it at all were presented with assurances that "only the minimum information needed to improve patient care" would be used, but no details were given about what form that use might take or who the users of their data might be. This left patients to make decisions about whether their data could be used without any clear explanation of what it might be used for. To compound this, opt-out forms were not supplied with the leaflet but left to GP practices to produce, resulting in over 100 variations (Vezyridis and Timmons 2016). Within a few weeks of the leafleting campaign, over 1 million people, or nearly 1 in 45 citizens, had chosen to opt out.

The NHS/DeepMind collaboration

A more recent case suggests that little has been learned from the care.data debacle. Google's Artificial Intelligence subsidiary, DeepMind, began working with the Royal Free NHS Foundation Trust in 2015 to develop an app for detecting

acute kidney injuries (AKI). The collaboration prompted a series of mainly positive articles in the technology, healthcare, and mainstream media.[9] Co-founder Mustafa Suleyman gave presentations at key conferences including the Kings Fund in 2015 and the Royal Society of Medicine in 2016. Laudatory coverage ended abruptly on 29 April 2016 when Hal Hodson, then a journalist at the New Scientist, disclosed the contents of an Information Sharing Agreement (ISA) granting the company access to five years of data, on 1.6 million patients, most of whom had never been diagnosed with kidney disease. Questions about why access on this scale was necessary and whether it was compliant with existing health data regulations began to dominate coverage, which spiked sharply[10] after Hodson's article appeared. The case is emblematic of the broader challenges the increasing use of private sector solutions for public sector problems provokes (c.f. Neyland and Milyaeva 2016). As Powles and Hodson explained.

> Without scrutiny (and perhaps even encouraged competition) Google and DeepMind could quickly obtain a monopolistic position over health analytics in the UK and internationally. Indeed, the companies are already in key

> *positions in policy discussions on standards and digital reform. If a comprehensive, forward-thinking and creative regulatory response is not envisaged now, health services could find themselves washed onwards in a tide of efficiency and convenience, controlled more by Google than by publicly-mind health practitioners. Aggregating and centralizing control of health data and its analysis will generate levers that exist beyond democratic control, with no guarantees except for corporate branding and trust as to where they might end up (2017, 357).*

The concerns expressed by Powles, Hodson and other campaigners were borne out, at least in part, when the Information Commissioner's Office (ICO) ruled in July 2017 that the Royal Free Foundation had failed to comply with data protection law and "could and should have been far more transparent with patients as to what was happening."[11]

Problematic Objects and Digital Tools

These incidents have many of the features attributed in STS scholarship to a classic socio-technical "issue." An issue arises when existing political institutions cannot deal with adequately with a particular problem. In this case, the issue of health data sharing, the flawed opt-out form designed to deal with it and the

news story, respectively, make an emergent 'concerned public' visible and force existing institutions to respond. The concept of "issues" has been elaborated in STS most explicitly by Noortje Marres (2005a; 2012). Issues, in Marres' account, are objects around which concerned publics gather when the consequences of particular actions are articulated as shared. This concept, which draws on John Dewey and Walter Lippmann's debate about technical democracy, shares lineage with other troubling objects in STS. Controversies, for instance, have a long history as a methodological trope that helps researchers unpack taken-for-granted dichotomies allowing access to facets of social and technical life that would be invisible, or black boxed, when everything is running smoothly (Callon, 1986; Latour, 1987; Marres and Moats, 2015). Matters of concern, like issues, have been used to describe objects like climate change that are complex, distributed, and composed of heterogeneous actors but do not necessarily turn on controversies over knowledge and science (Latour, 2004).

Yet the patient data case does not quite fit the parameters of a lively issue, controversy, or a matter of concern. While there have been spokespeople for

"the public" and opposition groups, the issue seems to have been "displaced" (Marres 2005a) or dispersed from "the public" to arenas like the legal sphere, social media, and technical discussions. Attempts to publicize the issue through leaks and reports have not resulted in a cohesive opposition or coherent alternative propositions. So how do we study what appears to be a dormant issue when many STS scholars regard issues or controversies as best studied when they are "hot" (Callon et al. 2001; Venturini 2010)?

In their discussion of recent government attempts to apply market logics and mechanisms to "solve problems," Neyland and Milyaeva (2016) draw on several insights from the history of STS about problems, such as their reciprocal relationship to solutions. But what exactly is a "problem" and how does it relate to the more familiar concepts of controversy and issue?

In one of the earliest discussions in STS, Callon (1980) argued that the definition of problems in science often implies their likely solution *and* the collection of actors poised to solve them. These highly contingent articulations,

or "problematisations" (Callon et al. 1986), are a fundamental aspect of power and enrolment into networks. What distinguishes problematizations from issue articulations[12] is that the former are inextricably, if implicitly, linked with particular solutions, and that they tend to arise within expert communities rather than "in the wild" (Callon et al. 2001). We might also associate problematizations with a logic of problem solving, or dealing with problems in a procedural way "...accepting the problem-definitions already on the table" (Zuiderent-Jerak 2015). Within STS, however, 'problems' appear to demand radical shifts in existing frames of reference.

In another formulation, Martin Savranksy (2018) linked problems to the work of Isabelle Stengers and Deleuze. Stengers (2000) has used the concept of "events" to describe occasions for which there is a definite 'before' and an 'after'. It is through these temporal stages that the identities of the entities emerge--they are not given before it. Savransky explains that events are inherently "problematic." This is similar to Dewey's formulation of the "indeterminate situations" that precede problems. Events demand that possible

futures be accommodated in the present but leave open the question of which actions should be taken. We might then use the term "problematic events" to describe situations prior to their settled definition and prior to the attachment of assumptions, procedures and "devices" (Marres 2012) that make them more determinate. In this formulation, problems exist independently of any attempts to articulate them. Problems are not a construct of the researcher but are an actual tension in the world (Dewey 1938). They have what Savransky describes as a "thickness", a material presence, even while their contours remain elusive.

Yet while problematic events may exert an actual force, we have no empirical access to them *except* through our attempts to articulate them. This moment of articulating or describing a problematic event is what STS researchers mean by problematization -- the process that transforms events into lively issues or problems. The question then becomes, what does it mean to study problems as problematic events, events that lack settled definition? Can problems help us understand situations that do not conform to our understanding of issues, that have yet to acquire publics, or that are not fully-fledged controversies? Is there

an analytic advantage to be had by embracing indeterminacy rather than trying merely to study and criticize existing problem definitions? Below we explore these questions by staging an empirical experiment using the kind of digital methods originally developed to study issues and problematizations as defined in STS. The results describe a case for maintaining an open and exploratory attitude both to problem definition and the role digital tools might play in addressing them.

Digital Tools

Studying controversies or problems has been associated with ethnographic, qualitative textual, and archival analysis (Latour 2005, 1988); but there is another tradition of using quantitative tools for making them visible. For example, the co-word analysis technique was developed to map "shared problematisations" (Latour and Woolgar 1979; Callon, Law and Rip [eds.] 1986). Scientists advance their projects by articulating the problems of different actors as shared--thus enrolling different parties. So, the problem of discovering some elusive protein becomes the problem of developing some measurement

device. Using a corpus of scientific abstracts, Callon and collaborators selected certain terms known to index problems and counted the number of times they appeared together. The more often they appeared together, the stronger the association. By visualizing these connections as a network, and comparing networks over time, the emergence of new instruments, natural phenomena, and even scientific fields can be seen.

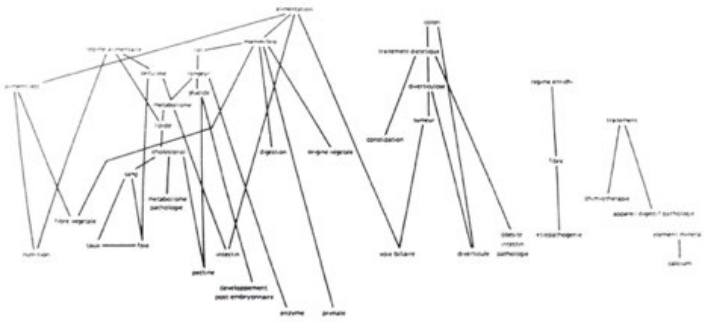


Figure 2. Co-Word Network (from Callon et al., 1986).

Inspired by work in scientometrics, STS researchers later developed a tool for mapping public issues on the web. Issuecrawler maps a network of the hyperlinked actors that gather around particular issues. The user inputs a series of websites and Issuecrawler collects all the hyperlinks on these pages, and then

all the hyperlinks on those pages for a set number of iterations. Then, by filtering out pages which have less connections than others, it reduces the larger network to reveal the most connected websites. Issuecrawler maps often reveal a mix of government bodies, NGOs, multi-national corporations, blogs and news devoted to the topic and how they link (or do not link) to each other. Interesting patterns can emerge from the presence and absence of links, for example, when an NGO links to the relevant government agency but that agency does not reciprocate (Rogers and Marres 2000). This suggests how certain actors control the shape that the network takes and the channels through which information becomes available.

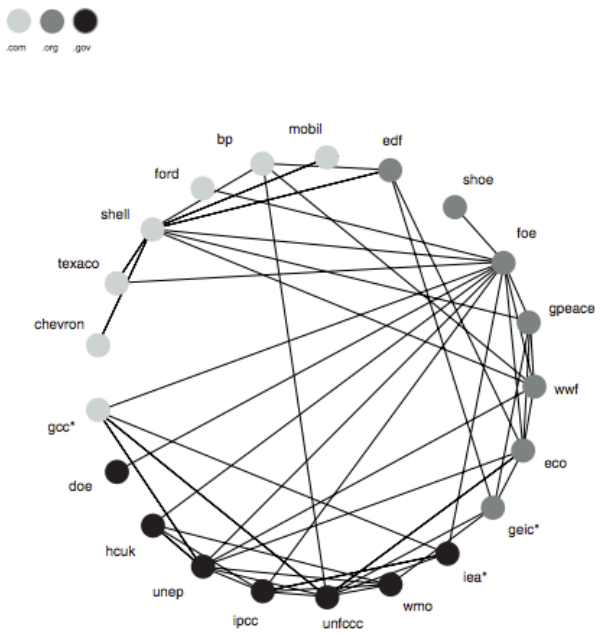


Figure 3. Issue-Network (from Marres and Rogers 2005)

More recently, researchers have used social media platforms to map issues, especially Twitter. Twitter is interesting, because, like home-made pages in the early days of the web, it has an anarchic quality, which means that it potentially overwhelms the restrictive framings and problem-definitions of large institutions and thus has the potential to disclose emergent publics (Bruns and Burgess 2015; Marres and Weltevrede 2013). Marres and Weltevrede have used co-hashtag networks, inspired by co-word networks, to create networks of hashtags appearing together in tweets. These can be viewed over time using a

tool called the "associational profiler," which ranks the hashtags most associated with other hashtags.

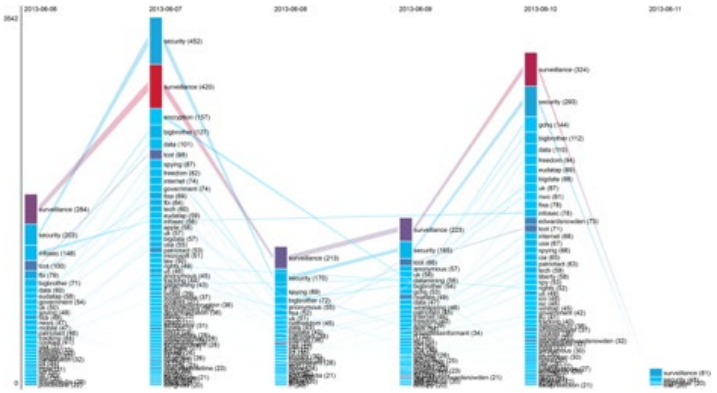


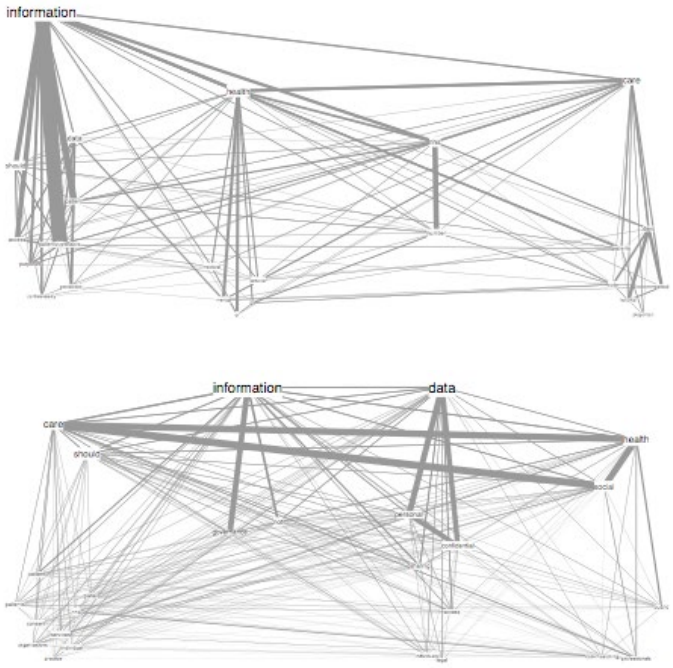
Figure 4: Associational Profile (from Marres and Moats, 2015)

The graph presented in Figure 4 shows the top hashtags associated with the hashtag #privacy over a period of a week. It shows how ambient concerns around personal privacy become both more focused around a few key tags (#prism, #surveilance) and more politicized (#bigbrother, #obama) following the 2013 revelations about the NSA collecting data on US citizens. For Marres, these tools make partially visible the elusive moment of "issuefication," when indeterminate situations start to take shape.

So, within STS, digital tools have been helpful for researching problematizations and issues. In fact, as issues become more distributed and complex with more players, publics and information, they may *demand* mapping techniques to make sense of them (Venturini, 2010). The challenge is that, as noted earlier, not all problems take the form of well-defined issues or controversies; nor do they all coalesce in accessible, structured venues such as the web, twitter or scientific journals. There are no existing tools for detecting problematic events in the raw, general sense prior to their articulation and this may, by definition, be an impossible task, because these tools rely on there being particular articulations of a problem out there in public that can be latched on to. Nevertheless, we attempted an experiment: to map the problem using these tools to see to what extent this case conformed or exceeded the classic STS understandings of problems, and to see how this excess could be mapped, if at all. This was not a "controlled experiment" in any formal sense but an open-ended exploration of the methodological challenges involved in studying problems.

Institutional Problematizations?

Perhaps the easiest place to start searching for the problem is within the set of institutions that ultimately failed to contain it. In 1997, Dame Fiona Caldicott was tasked with writing a report about information governance (Department of Health 1997). In 2013 she was asked to write a second report just before the care.data scandal and prepared a follow-up in 2016 as a direct result of the scandal (Caldicott 2013; 2016). To help understand how the problem of patient data has shifted over time, we produced a sequence of co-word maps for the first, second and third (2016) reports.[13]



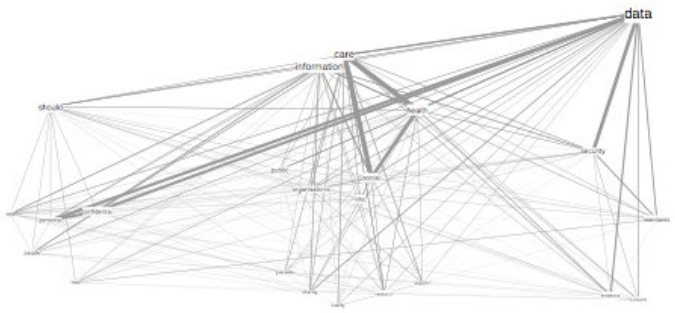


Figure 5: Co-word of terms in the Caldicott Report (1997 vs 2013 vs 2016) ranked vertically by degree (number of connections) and arranged horizontally by cluster[1]

Between these three graphs there are obvious shifts in terminology. This has as much to do with the time in which they were written as with the content of the reports. "Information," for example, is supplanted by "data" as the key buzz-word while names like "Health and Social Care Act," "Health and Social Care Information Centre" create tight clusters between those words. These terms and how they are linked have performative effects. That the words health and care come together is not just a linguistic accident but a clue that material transformations are at stake . The coming together of "Health and Social Care" as acts of governmental speech, signals a new policy objective to connect the data infrastructures of health and social care services. That the restructuring has not yet adequately connected health and social care infrastructures and practices,

does not diminish its significance as it has had a major and undesired overflow effect -- making citizens very nervous about what could happen to their data.

There are substantive elements that do, nevertheless, come through. The cluster of words that includes "individual," "patients" and "confidentiality" in the first map shifts to a cluster that prominently includes "public" and "people" in the last map. This reflects the shift in rhetoric from confidentiality and data sharing as a personal, individualized issue to a shared concern (both in data protection and data use for public health). But to understand more about these shifts we need to dive into the reports themselves.

The problem in the first report was framed in terms of information security: that is making sure the information stayed within the NHS and was properly anonymized. The report mapped various information flows and demanded that patient identifiable data should be shared only when necessary and in their most minimal form. NHS 'Data Guardians' were created to enforce these standards. This solved the problem as defined in the early report. Yet, in doing so, it

created another problem: NHS workers were so scared of data breaches that they were reluctant to share data between trusts and, especially, outside the NHS (Department of Health 2012). This relates to Neyland and Milyaeva's (2016) point that solutions to problems often generate their own problems. In the second report, in 2013, the emphasis shifted to ensuring data were made available for "direct care," including research, commissioning, or public health through implied consent, while any other, "secondary" uses would require explicit consent.

When care.data was eventually announced, the Department of Health did not anticipate the degree of outrage over *private* companies--particularly those from sectors like insurance and marketing--accessing and using the data. In February 2014, *The Telegraph* published a story claiming that NHS data had already been sold to insurance companies and were being used to inform increases to the price of critical illness insurance policies (Donnelly, 2014).[14] By then, care.data was on hold. The third Caldicott report (2016) focused specifically on this consent problem using a survey and focus groups. These more traditional technologies of

participation perform very specific assumptions about the nature of public opinion (Lezaun, 2007) that translate the issue in particular ways. The report remarked that public views on data sharing had changed little since 2013. People still accepted that their information would be used to support their care and found it frustrating to repeat the same information to different healthcare professionals. Views about information being used for purposes other than "direct care" were more mixed, with some "suspicious that information might be used by commercial companies for marketing or insurance" while others "prioritise the sharing of information to improve health and social care, and for research into new treatments" (Caldicott, 2016: 6).

These findings accord with a Wellcome Trust (2016) report exploring public attitudes to commercial access to data. This began by acknowledging that, when asked, most people say they do not want their health records shared with private companies. However, this unequivocal position should be measured against the low level of public understanding of how healthcare works. Research participants "did not know that commercial companies already play a part in

delivering healthcare and biomedical research." They had little understanding of existing safeguarding regulations or how the NHS already uses anonymized data for which no opt-out is available.

This all frames the problem as one of communication rather than of taking seriously public concerns about the privacy, efficacy, and security of data-driven research. The third report elaborated the consent model and tried to specify precisely where the distinction lies between direct care, that does not require consent, and secondary uses, that do. For medConfidential, an activist organization advocating patient rights and privacy in relation to their data, the distinction was still too vague. What about secondary uses that lead eventually to direct care? Do they require consent? If so, what time period has to elapse? As Powles and Hodson put it, "institutional and regulatory responses are insufficiently robust and agile to properly respond to the challenges presented by data politics and the rise of algorithmic tools in healthcare" (2017, 351).

In this case, while co-word analysis does give us a broad sense of changing language over time, the problematizations are under-specified in the maps. This could be because of the slightly different approach used by Callon and his colleagues or it could be because of the formal differences between scientific abstracts and lengthy policy documents. It is also possible that the problem arises from the repetitive and somewhat vague tone of the language often adopted in policy documents. In any case, we are confronted by the fact that these documents are only the outward manifestation of more complex back-room discussions and other techniques and processes like focus groups and surveys.

Issues

We explained earlier how the care.data opt-out forms became a device that allowed opposition to the proposed changes to be counted. The forms provided some means for an incipient public to express itself, but this was curtailed by a multiple-choice format that left no space for nuanced or alternative formulations. So, where else might this public-in-the making materialize? In 2015, we used issue crawler to see if we could detect an issue network. We

tried several different configurations of the key actors (the HSCIC, Department of Health and the care·data programme), but the crawl returned mostly actors that were not issue-specific· It tended to get stuck in either collections of conventional media and social media websites (Facebook, Twitter, BBC) or in the labyrinth of over 3000 NHS websites[15]·

Figure 6. Issuecrawler co-link map using starting points: http://digital.nhs.uk, http://www.hscic.gov.uk, https://medconfidential.org, https://www.england.nhs.uk/ourwork/tsd/care-data, https://www.gov.uk/government/organisations/national-information-board

One possible conclusion we could draw is that these maps show that there is no public issue here. It is equally possible, however, that this negative result is an effect of the medium. This raises some interesting questions about how digital methodologies and tools work and how they cope with a rapidly changing, mobile and responsive web environment. Different types of organization use websites in different ways, and websites themselves are used differently today than they were when Issuecrawler was developed. The NHS tends to use links pages to direct users to relevant organizations and contact points. Opposition groups like medConfidential do not link to the NHS but rather primarily to news stories and likeminded organizations for example Privacy International and Big Brother Watch. These differences in how links are used mean that Issuecrawler may not map the connections between organizations with an issue in common. In an effort to work round this, we turned to colleagues working on the BiMeDa project[16] who provided us with an expert curated list of the key players. Rather

than using the issue crawler to "discover" the issue network, this allowed us to map the politics of linking within the network through an "inter-actor" map.

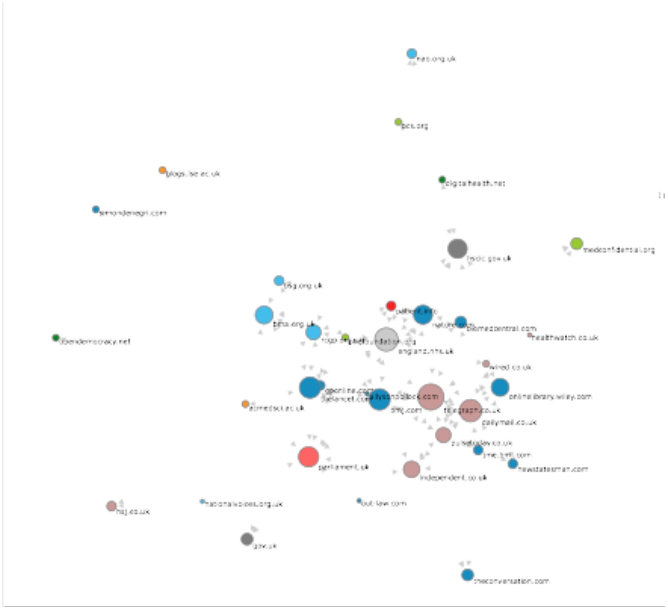


Figure 7. Issuecrawler "interactor" map of actors supplied by the BiMeDa project in Jan 2016

In this curated list, NHS bodies link internally, but neither they, nor medConfidential, link to each other. The two do not appear as distinct clusters in the map only because established media and specialized blogs stitch the issue together by linking to both. The issue, at least as defined qualitatively by our BiMeDa colleagues, does not appear to take the familiar shape of past issues,

either because of the indeterminacy of the issue and its boundaries, or because of shifts in the way debates happen online. This is not to suggest that the issue or debates are not happening "out-there" in public: we knew from the documentary analysis, participant observation and interviews that many of the key debates, discussions and decisions about patient data were happening--not on the web per se, but across a loosely connected network of private and public meetings as well as on blogs and social media.

Social media may offer a more dynamic platform for the discussion of data than the web. It extends and enhances the internet's capacities to reconfigure proximities, altering what it means to be present and absent from the physical locations at which debate is taking place. This became clear to us as we moved between attending conferences and tracking the activity around their hashtags. We collected Tweets from Kings Fund Digital 2015 (#KFDigital15), Stanford Medicine X (#medx) and the Financial Times Digital Health Conference (#FTDighealth). We then combined and visualized them as a composite co-

hashtag network: hashtags that appear in the same tweet are connected and the more times they appear together the stronger the connection.

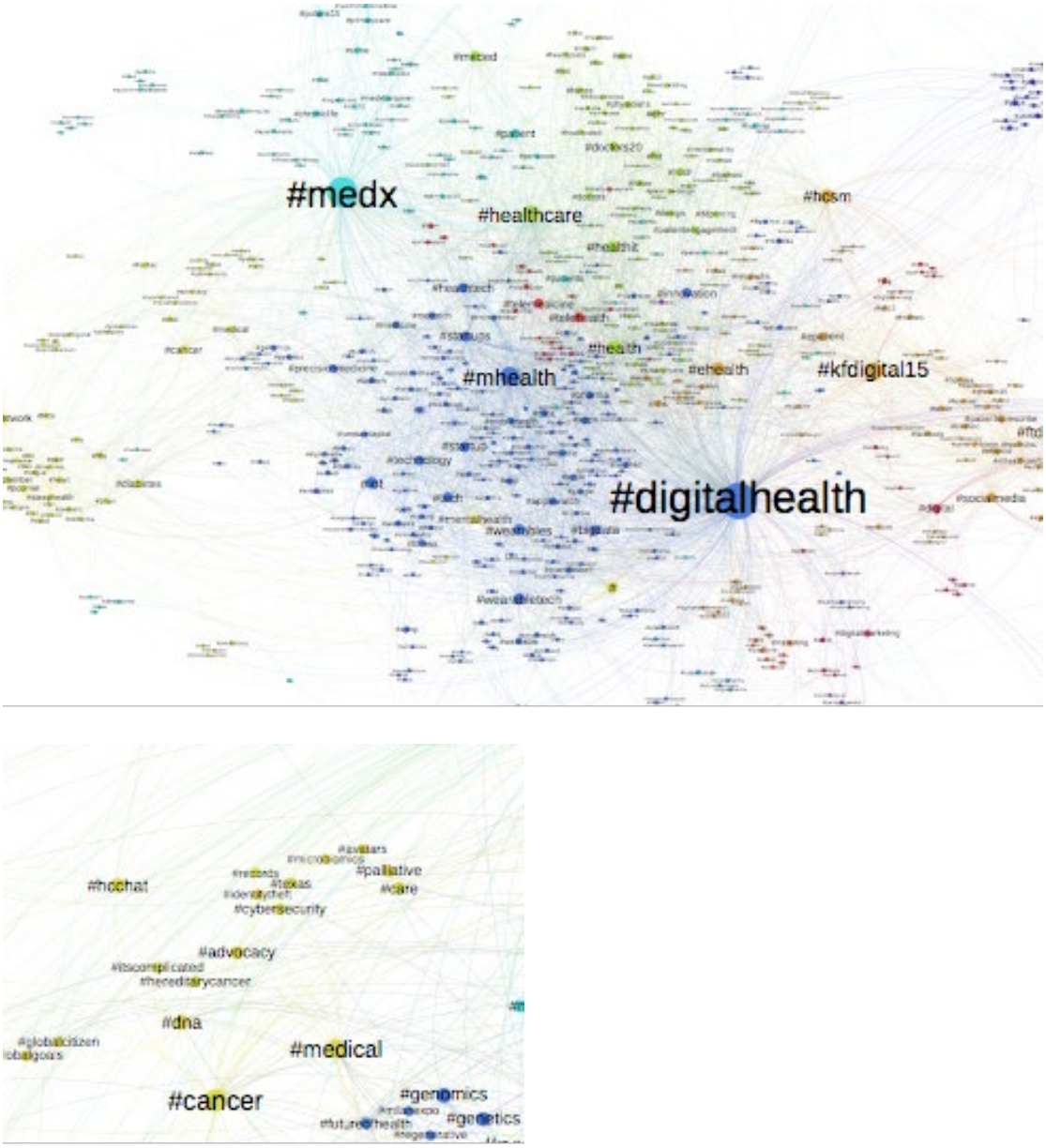


Figure 8. Co-hashtag map of digital health conference hashtags in 2015 (detail below)

These conferences took place in different continents and timezones, but there was significant overlap in hashtag use and in users· Different names (#mhealth, #ehealth, #digitalhealth) for the complex intersection of tech and healthcare can be seen vying for attention· We were again unable to detect a lively issue· Only a tiny cluster of hashtags (see detail of Figure 8), within a space devoted to data and healthcare, referred to privacy concerns or care·data specifically· These included #privacy, #identitytheft, #records, #protectourdata, and on the other side #freethedata, #datasharing and the campaign #datasaveslives· These hashtags present different articulations of the issue but they are emerging from only a handful of privacy specialists and an even smaller group of data sharing advocates· It is possible that the issue was obscured by the sector's characteristic hyperbole of self-styled "influencers" and promotional discourse, but, again, it is also possible that it is no longer a vibrant issue on Twitter, several months after the care·data programme was paused in February 2014· The map does elucidate the generally accepted terms of the debate: privacy is a right that must be protected, but data might save lives/funds· Both sides of

the debate accept these premises and frame the issue as a trade-off differing mainly on where they draw the line (Zarsky, 2016). One user made exactly this point in a presentation slide.[17]

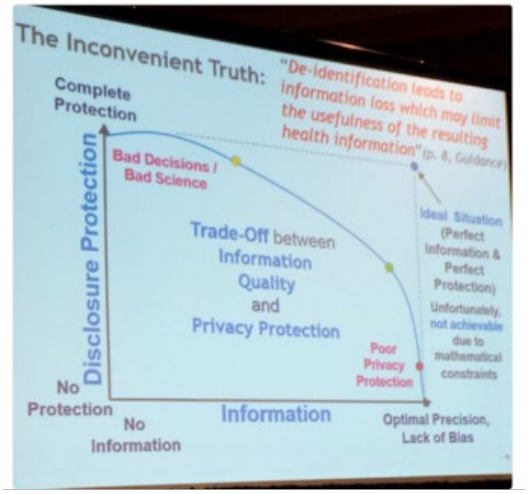


Figure 9: Tweet by Joe_stringer1: rt @bleddyn_rees: #digitalhealth #bigdata not convinced it is one or the other choice. #privacy https://t.co/5hkarprsh8-Joe_stringer1 Sun Jun 14 21:04:30 +0000 2015

Research in STS has complicated the debate about trade-offs in data sharing. Gregory and Bowker (2016) question whether complete privacy is logically possible. Seeing the self, "the citizen in there (beneath the naked skin) and data about the citizen out there (circulating within ever denser industrial and

governmental networks)" they argue, is misconceived (2016, 211). The very concept of the self is contingent on its representation through data. Others have debated the idea that large digital datasets, in themselves, can even solve problems, let alone save lives (boyd and Crawford, 2012; Poon, 2016; Uprichard, 2013). These debates are important but they offer little guidance about how *particular* patient data could be leveraged to solve *particular* problems. Part of the challenge is the very framing of private consequences and public benefits as conceptually distinct (Birkbak, 2013; Marres, 2005a).

A more methodological challenge concerns the distinction between private and public settings. What gets discussed behind closed doors, in putatively "public" forums or in the hybrid locations between? What materials become accessible to the researcher? In June 2015 team members attending the King's Fund Digital Health and Care Congress soon noticed that conference participants were using social media and face-to-face interactions to continue earlier conversations. We noted multi-site, multi-platform conversations moving across public Q&A discussion sessions, private face-to-face, Facebook, Twitter and the conference's

own bespoke messaging platform. There was talk during presentations using social media, during Q&A sessions and breaks involving both delegates and people who were not at the conference but "following" it through the hashtag.

These patterns of interaction, and the problems, issues and controversies that underlie them are not apparent in the hashtag activity we tracked. Field notes of the events reveal that patient data, and care.data in particular, were frequently invoked by delegates as "issues" in achieving the digital health visions promised in policy reports (Department of Health, 2012; 2014). At conferences, but not so much on Twitter, care.data was shorthand for how far the NHS was from the Department of Health's paperless, digital-by-default vision.

Figure 10. Jeremy Hunt and Tim Kelsey on a visit to Silicon Valley, September 2015

One episode stands out. Malay Gandhi, then CEO of Rock Health, a digital health venture capital fund, mentioned in conversation with one of us that Rock Health had that morning hosted a delegation including the then Secretary of State for Health, Jeremy Hunt and Tim Kelsey, at the time the NHS Director of Patients and Information and chief architect of care.data. The trip was not secret but neither was it widely reported. Given that Jeremy Hunt was that same week dominating headlines in the wake of the controversial changes he

proposed to the junior doctors' contract and the still unravelling mess of care·data, the Silicon Valley visit might have garnered some attention· Care·data, the new junior doctors' contract, and the role of private technology companies in the NHS all touch on deep sensitivities surrounding what, for many, amounts to stealth privatization of the NHS[18]· So, on one hand, it seems that potentially important decisions about patient data are not happening in plain sight on the web or Twitter, and yet, paradoxically, Twitter can be the means that reveals them·[19] Social media, Freedom of Information (FoI) requests and leaks all problematize the boundary between public debate and private decision making, and this distinction, on which some digital tools rest, is at stake in the problem·

Problematic Events

While the concepts of problematization and issue, and the tools associated with their analysis, have been helpful for thinking through the case, they have to some extent failed to define or explain the problem we are in search of· We

decided to experiment with another way of mapping the patient data sharing problem which did not rely so heavily on these well-established spokespeople, devices and representations. Since problems tend to straddle public debates and closed expert discussions, is there any way of seeing what lies between the two? As mentioned earlier: there are no ready-made tools for tracking problematic events, but with the upheaval they create, they should be detectable, if not fully representable. One recurring character throughout this story has been journalists, who stitched together the issue network and, through leaks, provided much of the drama. Perhaps we can map their interventions? Our strategy was to first start with a kind of appropriate baseline, a grey backdrop against which the before and after could become obvious. We chose some search terms ("NHS," "patient" and "data") to collect news articles in the period Jun 2013-16, using a toll called the Google News Scraper, which queries the search algorithm for news articles (based on Google's highly contingent categorization of news). This would allow us to visualize the general topic area in which the problem might emerge.

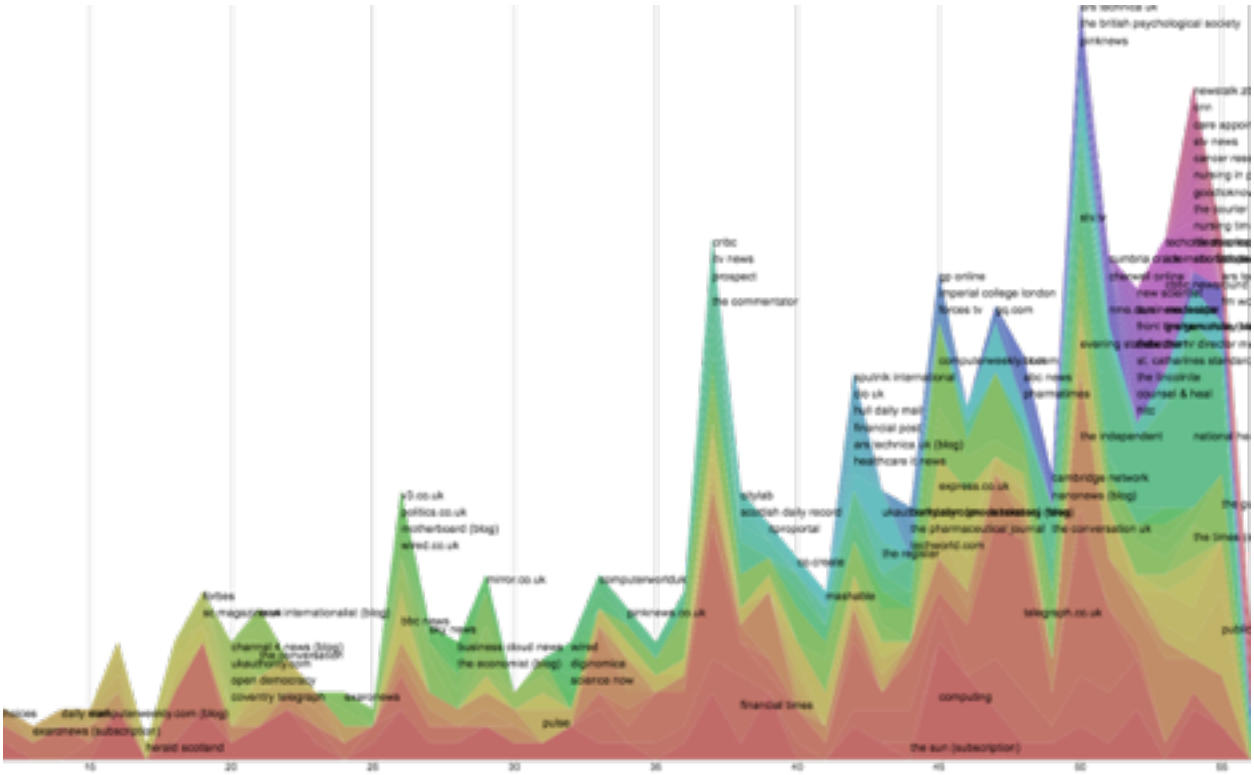


Figure 11: Streamgraph of articles containing the words "NHS," "patient" and "data" – according to Google News API.

In Figure 11, above, the corpus of articles was grouped by media outlet (e.g. bbc.co.uk) and by day, and then visualized as a stream graph. Each coloured band corresponds to a specific outlet, from bottom to top, in the order in which they first appear in the data set. From this data, we could deduce that the topic has exploded over time, but this would be hasty. Google's algorithm favours more recent articles because some articles have been deleted or archived and because the crawling bots constantly discover new sources. This means that

not all the growth is as event-driven as it appears. What is more striking is how the *number* and variety of media outlets involved grows near the end. The collective centered around the topic becomes more heterogeneous as it moves from more specialized coverage in healthcare and tech to a more general audience. The event multiplies the number and variety of entities that are concerned with the problem.

If we examine the various spikes, all of which more-or-less correspond to scandals or events, and analyze some of the articles that make them up, we can see that most of them refer to care.data, including the leaflet campaign itself and Tim Kelsey's resignation. The second biggest spike (towards the right of the graph) relates to the Google DeepMind story and it dwarfs the earlier spikes. This is the aftermath of *New Scientist*'s report that the DeepMind/Royal Free Trust agreement went far beyond what had been announced publicly and specified that the data need not be anonymized. However, in an editorial, Suleyman pointed out that Google nonetheless did anonymize the data as a matter of protocol.[20] Also, other organizations have had access to similar data sets, and

there are clear prohibitions against using the data commercially. As successive governments have opened the door to private providers, contractors, and consultants, it has become harder to disentangle the "public" NHS from "private" corporate interests. This raises the question: what is it about Google DeepMind that caused such a stir? Is it perhaps because Google, particularly its AI wing, kindles sci-fi scenarios? Or is it because of the obvious potential for commercial uses of this data linked to Google's main business: online advertising. This scandal discloses conflicting attachments between NHS organizations and private companies, on the one hand, and doctors and patients, on the other (Marres, 2005b). It also showcases overflows in what the 2016 Caldicott report defines as "data for direct care," which does not require explicit consent, and "secondary uses" which does As Powles and Hodson (2017) argue, the Royal Free/DeepMind ISA is careless with the crucial distinction between data for direct care versus data for secondary uses. The experiment was speculatively using data, only a portion of which had the potential to contribute to acute care technologies, therefore much of the data used, in all probability, did require explicit consent.

The biggest spike, however, relates to stories about the junior doctors' strike. When Jeremy Hunt proposed a new contract, many revolted, arguing that the new proposals for weekend working--referred to as a "seven day NHS,"-- would reduce patient safety. The public protests were galvanized by a concern that the resulting chaos was a deliberate ploy in an ongoing plot to privatize the NHS. Problematic events are always situated, and positioned in relation to other problems, controversies and events in the larger field (Barry, 2012).

We could say that the emergence of the junior doctor's strike in this dataset is an artefact of the data extraction process: since the strike dominated the news, any story that mentioned "data," "NHS," and "patients" would be counted. "Data" could also refer to non-patient data or even appear elsewhere on the page. We could also say, however, that the doctor's strike looms large over the data breaches. One explanation for the Conservative government and the Department of Health's interest in algorithmic and digital healthcare is that by taking key tasks, like triage, out of doctors' hands, they could increase efficiency

while diluting the collective power that the British Medical Association, the body that represents junior doctors, has historically wielded.

The graph says as much about Google as it does about the case. The distinction Google makes between news and blogs is arbitrary, as is the bias towards the new at the expense of the old. While the baseline helps us to pick out variation, the event *redefines the baseline* and we should not make strong claims about the prevalence of stories. It is undeniable, though, that the problem seems far more lively in this journalistic arena than on the web or social media. Also, since we picked a very general phrasing of the problem, this graph expands our understanding of the entities and issues to which the problem is connected. Finally, this graph gives us some sense of the force required to develop the problem and gather these entities. If we look at some of the main spikes here, and ask ourselves where these shifts in the controversy come from, it seems clear that while a handful are driven by NHS announcements and the initial public outrage, news outlets are a key driver of the controversy.

This raises interesting questions about our own involvement in the problem and possible ways to intervene in it. If news articles and editorials have a seismic effect on the problem, then social science descriptions, hidden behind paywalls and dense academic prose, are probably not the most effective mechanism for intervening. In our project, we experimented with using a blog, participating in social media debates, and using our digital tools as engagement techniques to enrol informants and (hopefully) shift the conversation; but we may need more visible venues to publicize the problem.

Conclusion

In this paper we used a series of digital tools to track an elusive problem and found that these tools, which are adapted to the study of expert problematizations and public issues, failed to capture the empirical case. Obviously, the legal definitions of the problem, as revealed through our co-word analysis of the Caldicott reports, generated new problems that needed to be addressed. Yet these problems did not seem to manifest themselves as issues, either through their web presence or on Twitter. The question then becomes: is

this a failure of the tools, bad study design a lack of knowledge on our part, or is the situation *actually* indeterminate in Dewey's sense?

Research tools may simply be unable to represent problems, understood as problematic events. Problems infect and confound established tools, destabilizing categories, identities and assumptions. As Isabelle Stengers notes, they change the researcher as well (1999), forcing them to rethink what is being studied. This point is well understood in social research. While we have used digital tools to draw attention to it, the difficulties we encountered are comparable to those encounters in qualitative research. Who are we interviewing? Does the controversy play out in policy reports, online, behind closed doors? These are dilemmas are an inherent part of the empirical problem.

Bluntly, our digital tools failed. Yet we learned a great deal about the case by experimenting with them. They allowed us to move between different arenas very quickly without deciding in advance where the problem manifested itself. We learned that it is counterproductive to frame the issue as a trade-off between

individual security and collective benefits. A much more useful approach might emerge from articulating specific, contextual rather than general or universal relationships between the two. Digital tools also allowed us to see the problem being displaced to closed, but still leaky spaces, which journalists, leaks and scandals have the power to re-publicize. Finally, we learned that despite the instability of distinctions between public sector and private sector entities, notably in the operational co-dependence of the NHS and private suppliers, these entities are constantly leveraged as a rallying cry for concerned publics. Existing governmental articulations of patient data sharing as a technical matter that can be dealt with by communication, encryption and opt-outs, have seemingly failed in their attempts to sideline legitimate political concerns about privatization and the historical tensions between the government, the Department of Health and the medical profession.

There are a few take-aways from this experiment. First, maintaining a broad and open definition of the problem matters. Dwelling in the indeterminacy, rather than stepping on the firm ground of our own or others' problem-definitions,

means getting a better sense of what is at stake and how things could be otherwise. Second, it seems clear that we need methods that adapt to problems rather than relying on readymade solutions. In the course of our research we had to modify the Issuecrawler to make it work and fashion a simple-bespoke visualization to map the journalistic issue space. Both qualitative and quantitative methods are tied to types of empirical materials and devices, and to certain assumptions about social life. Taking problems seriously means considering different locales, corpuses of texts and other forms of research outputs and public interventions--moving past detached observations to active participation in developing the problem. In this case journalists, practitioners and advocates who were active on social media were among the key actors, so we felt it was appropriate format for us to disseminate research through social media and blogging as well as through more conventional academic dissemination. But there are other avenues to explore.

This case centres on the use of digital tools, such as machine learning and artificial intelligence, which are, just like the tools we used, often tied to

specific, narrow problem articulations and data sources. If we are permitted a leap, we might suggest that these tools could also be used in a more open, exploratory, and questioning way. So rather than using digital techniques to contain, capture, or eliminate problems, they might also be used to *develop* a problem – to gather publics and allow alternative definitions of the problem to unfold. This would require embracing uncertainty and indeterminacy about the limits and difficulties of working with digital tools.

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Endnotes

1 We refer throughout to the NHS England, NHS Wales and Scotland are separate organizations.
2 See Neyland and Milyaeva (2016); Savransky, (2018 forthcoming).
3 Insuring Healthcare in a Digital World; Wellcome Trust Seed Award 2015 WT108386AIA http://www.payingforhealth.com/research/; McFall (2015; 2017)
4 See Mittelstadt and Floridi (2016) Høyer, Tupasela & Rasmussen (2017)
5 Timmins (2012); Pollock, Macfarlane, Godden (2012); Krachler and Greer (2015)
6 General Practitioners working in primary-care
7 Renamed NHS Digital in July 2016.
8 Available from https://www.england.nhs.uk/ourwork/tsd/care-data/ accessed 20 Aug 2017
9 See https://www.theguardian.com/science/2016/mar/15/the-nhs-is-a-much-bigger-challenge-for-deepmind-than-go; https://www.theverge.com/2016/3/10/11192774/demis-hassabis-interview-alphago-google-deepmind-ai; Glyn Moody was one of the first to express a more cautionary note https://arstechnica.co.uk/information-technology/2016/02/googles-deepmind-ai-group-working-with-nhs-to-develop-patient-care-software/ all accessed 20 Aug 2017
10 See discussion of Figure 13
11 Available here: https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-with-data-protection-law/ accessed 20 August 2017
12 Throughout this paper we understand articulations, frames and problematizations to refer to both discursive and technological/ material attempts to render problems visible and solvable.
13 Using wordij based on the co-occurance of words in the same document within 5 words of each other, only top 30 words displayed, clustered horizontally by modularity algorithm in Gephi.
14 The story was almost accurate. It was the Institute and Faculty of Actuaries, that bought the data, and it was for a research report that did not recommend a pricing increase. *The Telegraph* corrected the error a week later.
15 Available from: http://transformation.blog.nhs.uk/designing-the-future-of-nhs-uk
16 Available here: http://www.bimeda-project.eu/actors.html accessed 20 Aug 2017
17 See https://twitter.com/n_brennan/status/610163591329787904

18 cf Stephen Hawking's broadside https://www.theguardian.com/science/2017/aug/18/stephen-hawking-blames-tory-politicians-for-damaging-nhs accessed 20 Aug 2017
19 See tweet available at https://twitter.com/amcunningham/status/647514515085459456 accessed 20 Aug 2017
20 https://www.theguardian.com/technology/2016/may/06/deepmind-best-privacy-infrastructure-handling-nhs-data-says-co-founder